
Review of Cross-Cultural Issues Related to Quality of Life After Spinal Cord Injury

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Quality of life (QOL) is a dynamic concept that means different things to different people, both in the general public and within the research community. Because of this, a common definition of QOL has been hard to achieve. This article reviews cross-cultural issues related to QOL research in spinal cord injury (SCI). Many factors influence QOL for persons with SCI, including observable and objective indicators and subjective self-report ones. The World Health Organization's International Classification of Function, Disability and Health is used in this article as a framework to better understand how these factors may influence QOL. A number of important steps are summarized with respect to measurement issues in QOL. A comparison between data from 2 countries (United States and Brazil) using the International SCI QOL Basic Data Set shows similarities in scores and good reliability in the Brazilian sample. Substantial, significant correlations were observed among the SCI QOL Basic Data Set items and the WHOQOL-BREF within the US sample. The article ends with a set of recommendations for the development of cross-cultural measures of QOL for use in the SCI population. **Key words:** cross-cultural, data sets, internationality, measurement, quality of life, spinal cord injury

Quality of life (QOL) is a widely embraced term, but its meaning is complex and not understood consistently. Like the concept of disability, it is contextual and relative to time, individual factors, and physical, economic, cultural, and social environments.¹ Even though disability has been defined by the International Classification of Function, Disability and Health (ICF) of the World Health Organization (WHO) to encourage international acceptance and cultural applicability, the term "quality of life" is not included in its framework. Concerns about this lapse have been expressed by the Committee on Disability in America in its Institute of Medicine (IOM) 2007 report.² According to the WHO, quality of life is "the perception of individuals of their position in life, in the context of the culture and the value systems in which they live and in relation to their goals, expectations, standards, and concerns."^{3(p153)} This definition is especially important to establish a common understanding of the concept and metrics that can be used across cultural and geographical boundaries, allowing for comparisons of clinical outcomes

and research. The purposes of this article are (a) to review the conceptualization of quality of life (QOL) in relation to factors that may influence its experience among persons with spinal cord injury (SCI); (b) to discuss measurement approaches to QOL applied to SCI research; (c) to provide a brief overview of cross-cultural data findings and trends; and (d) to present recommendations and a discussion of future directions for cross-cultural research on QOL after SCI.

This article is based partly on information presented at a workshop on international perspectives of QOL after SCI in Istanbul, Turkey, at the 2013 annual meeting of the International Spinal Cord Society.

Quality of Life: What Does It Mean?

QOL has been defined conceptually as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."^{4(p1570)} QOL definitions reflect variations in experiences across

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many factors, including the experience of disability and of living in different environments. QOL has been said to vary by country.⁵

Several authors have acknowledged the many difficulties associated with the subjective meaning of QOL.^{6,7} In spite of these difficulties, QOL assessments are increasingly used in rehabilitation and embrace a number of conceptual approaches and measurement tools.⁸ Clinical trials in rehabilitation have begun adopting QOL outcomes to indicate treatment effects in terms of participants' well-being and satisfaction.⁹

Qualitative studies have contributed to a more in-depth understanding of the concept of QOL following SCI.^{7,10,11} It has been reported that SCI participants have difficulty defining the term; they often define it as "doing what I want to do" or "enjoying what I have in life."¹² QOL is viewed as something that is created out of experiences (emergent) rather than something that is presented to an individual as a given. The concept is also defined in relation to a person's expectations. Being happy and satisfied appears to depend on individuals' ability to disregard things they cannot change. Ultimately, QOL relates to the ability of individuals with SCI to do things for themselves and to re-assume meaningful roles in family and society.¹³ This perspective reflects the overall components of the WHO ICF framework: function, activity, and participation. Referred to as the Rosetta Stone,¹⁴ the ICF provides a conceptualization of the many factors affecting QOL as it applies to persons living with disability. As such, it can be used to test the influence of cross-cultural factors on QOL after disability.

Factors Affecting QOL After SCI

There are a number of factors to consider when evaluating QOL differences among persons living with SCI across diverse environments. These include, but are not limited to, economic, racial, social, and cultural differences. Despite many studies on this topic, the role of these factors in influencing QOL after SCI is still unclear.

The cultural relativity of the QOL concept has been discussed by many.¹⁵ QOL is affected by personal choices, but it is also affected by the

cultural environment in which people are raised. Therefore, one can expect QOL outcomes to be culturally dependent. Yet only a few studies have looked at cultural and ethnic differences affecting QOL among persons with SCI in the United States.^{16,17} These differences largely reflect specific aspects of QOL, such as employment opportunities, participation, and economics. It is assumed that such differences are present when comparing QOL across countries, signaling a need to address such inequalities.

Hofstede¹⁵ provides a general framework for QOL comparisons in the context of employment by referring to societal values that define QOL across countries. His conceptualization provides a framework that can be used to better understand cultural differences in QOL among persons with SCI across 4 components: (1) power distance (the extent to which a less powerful person in society accepts inequality in power and considers it normal); (2) individualism (the extent to which an individual primarily looks after his or her own interests); (3) masculinity (the differences in roles for men and women); and (4) uncertainty avoidance (the extent to which people within a culture are uneasy about unstructured, unclear, and unpredictable situations). Many less developed countries fit within a quadrant of large power distances, suggesting greater social inequalities and health disparities and lower levels of individualism. Lower levels of individualism result in lower personal independence and greater interdependency for those living with SCI. In contrast, the United States is classified as being within the small power distance, indicating greater equality in society (eg, the Civil Rights Movement, Americans with Disabilities Act, Sections 503 and 504 of the Rehabilitation Act), and high individualism (eg, the independent living movement of the 1970s) quadrant. These differences in policies and access to resources are likely to result in corresponding differences in QOL for persons living with SCI. Objective indicators such as opportunities for employment, education, good health, and well-being are likely to be fewer in socioeconomic-deprived environments. However, the meaning of these lost opportunities may vary based on cultural values and personal expectations.

The idea that disability equates to negative outcomes is often embedded in QOL definitions, suggesting that the absence of disability promotes good QOL. This point was first mentioned by Albrecht and Devlieger in 1999 when describing the disability paradox: "Why do many people with serious disabilities report that they experience good QOL when to most external observers these individuals seem to live undesirable lives?"^{18(p977)} A theoretical framework was developed to explain this paradox. Accordingly, QOL is dependent upon finding balance between body, mind, and spirit in the self and on establishing harmonious relationships within the social context and environment. To fully explain the paradox, this framework must be tested across cultural environments.

The importance of the environment is highlighted in studies designed to determine the relationship between this concept and QOL after SCI. Noreau et al¹⁹ discussed the perceived influence of the environment on social participation among persons with SCI. A related study²⁰ found a strong relationship between social roles and QOL among older adults with physical disabilities and determined that QOL was associated more with the satisfaction with the accomplishment of life habits than with performance itself.

The value placed on different health states is not constant across the life span or among people with different health states. Hays et al²¹ cite the need to evaluate health-related QOL using measures such as the Short Form Health Survey (SF-36). A 2001 survey of disability rights activists showed that physical health was less significant to their sense of well-being than was generally found among persons without disabilities.²² Likewise, the concepts of health and disability appear to be viewed differently as a function of time since injury among persons with SCI.²³

Discussing social health factors affecting QOL, Miringoff et al²⁴ offered reliable information about 16 indicators of progress responsible for overall QOL that may influence the lives of those with a disability, such as SCI. These include accessibility to health care, quality of education, adequacy of housing, and opportunities for employment.

This perspective is complemented by Veenhoven's²⁵ concept of happiness, which is also used to assess QOL across nations. Happiness

is used in various ways to denote individual and social welfare. The quality of the living environment is a precondition to happiness. The concept of happiness is close to life satisfaction, which is described as a subjective measure of QOL and well-being. Happiness is related to economic development in a complex manner²⁶ and is related to positive health, resilience, and self-actualization.⁷ From an economic viewpoint, variations in happiness are expected based on each country's socioeconomic status.²⁷ Measures of happiness, however, are largely absent from the SCI literature, rendering cross-cultural comparisons impossible.

The notions of spirituality and religiosity have also been viewed as subjective dimensions of QOL. These have been studied by several authors in relation to coping with SCI.²⁸ Existential spirituality, a search for meaning in life, as opposed to religious spirituality was viewed as a strong predictor of QOL among a US sample of persons with SCI.²⁹ Cultural differences related to beliefs and religious preferences are likely to influence QOL among persons with SCI in other countries also.

The exact relationships among factors that can explain these contextual differences are still not fully understood. Domains of QOL in persons with SCI have been compared between Eastern and Western countries,^{30,31} as well as between developed countries in Europe and less developed ones.^{32,33}

In the United States, 2 meta-analyses were conducted on factors influencing QOL after SCI; they had inconsistent findings, concluding that more work is needed.^{7,34} A third systematic review, conducted later, highlighted the need for periodical assessments of QOL and the importance of selecting measures that are truly aligned with study objectives and creating study designs with strong psychometric properties to improve the understanding about factors that affect QOL and to identify strategies to improve QOL outcomes after SCI.³⁵

Measuring the Unknown

Whiteneck claims that "more disagreement exists on the definition and measurement of QOL than on any other construct that plays a critical role

in medical, rehabilitative, social and psychological research.^{36(p1075)} Multiple approaches have been used in studies that evaluate QOL in persons with SCI; the number of instruments nearly equals the number of studies.³⁷ This growth in studies and measures creates difficulties when attempts are made to draw conclusions. In research on the QOL of persons with SCI, many instruments demonstrate poor psychometric properties.

The measurement of QOL has closely followed the many conceptualizations of the construct and its components as mentioned above. The multidimensionality of the construct has posed many challenges to its measurement.³⁸ Studies utilizing subjective QOL measures have become more common during the last 15 years.³⁹ Despite their increased use, subjective measures lack the sensitivity to detect changes, lack standardization and norms for persons with SCI, and, most important, lack sufficient evidence of validity.^{6,8,40}

Persons with SCI experience considerable change in virtually all aspects of their functioning. The dynamic concept of response shift has been identified as key to assessing changes in persons with chronic illnesses. Its relevance to persons with SCI is clear.⁴¹ These persons undergo simultaneous changes in their internal standards, values, and conceptualizations of QOL. These changes, which are especially applicable to persons with new onset of disability, are referred to as recalibration, reprioritization, and reconceptualization response shifts. This has important implications for the measurement of QOL after injury, as it requires that measures be sensitive to change over time to be truly valid.⁸

Definitional and conceptual ambiguity about QOL poses a major challenge to the development of robust and widely accepted measures of QOL in SCI research. Similar issues were cited by Heinemann when discussing measures of participation.⁴² Issues of instrument validity and interpretation are even more complicated when considering cross-cultural comparisons and the need for meaningful translation. These problems prompted a series of new initiatives in QOL measurement that can be applied to SCI.⁴³

Ware⁴⁴ suggested a number of important steps in the evolution of the conceptualization and

measurement of QOL: (a) new formulations of the structure of health status designed to distinguish role participation from the physical and mental components of health for purpose of international studies; (b) applications of item response theory (IRT) in constructing better functional health measures and cross-calibrating their underlying metrics; and (c) use of computerized dynamic assessment technology, which may lead to more practical assessments and more precise scorings.

Following Ware's suggestions, Tulskey et al⁴⁵ developed a new way to assess QOL among persons with SCI. This new measure uses advanced psychometric techniques (eg, IRT, computerized adaptive testing [CAT], and item banking). The SCI-QOL is a SCI-specific patient reported outcome (PRO) measure of health-related quality of life (HRQOL) that covers 3 domains of well-being – physical and emotional health and social participation.

The growth of PRO measures in QOL resulted from the need to take into account both the multifaceted nature of QOL and patients' perspectives when assessing broad treatment outcomes that are truly relevant to their lives.⁴⁶ QOL is an increasingly important PRO across general and specific health populations and plays a critical role in the evaluation and comparison of outcomes from clinical trials.⁴⁵ Examples of PRO measures include the Patient Reported Outcomes Measurement Information System (PROMIS) and the Quality of Life in Neurological Disorders (Neuro-QOL). A specific HRQOL using PRO for SCI is the SCI-QOL, mentioned previously. It requires that items defining a construct be unidimensional and hierarchical. It includes calibrated item banks with items across the entire range of functioning that influence QOL. This approach to measurement ensures domain relevance and content coverage.⁴⁵ The SCI-QOL is currently undergoing validation with a large sample of persons with SCI representing several geographical areas of the United States.

A next step would be to test the SCI-QOL in cross-cultural samples with SCI. Like the International QOL Assessment (IQOLA) project developed by Ware⁴⁷ based on the SF-36, the SCI-QOL, or perhaps the ISCI-QOL, would need to

undergo 2 major steps before being ready for use across world populations. First, a protocol for translating and testing the measure would need to be established following a standardized process. Then, studies to evaluate the validity and equivalence of interpretation of scores across countries would need to be conducted.

Developing International Common Metrics: Preliminary Findings

In 1991, the World Health Organization Quality of Life (WHOQOL) project developed an international cross-culturally comparable QOL assessment instrument, the WHOQOL,⁴⁸ to measure peoples' perceptions in the context of their cultures and value systems, personal goals, standards, and concerns. The WHOQOL-BREF is a short version of the WHOQOL and comprises 26 items that measure the following broad domains: physical health, psychological health, social relationships, and environment. It has 2 global items: Global QOL and Satisfaction with Health. The measure has been used in several studies of persons with SCI.^{49,50} The WHOQOL-5 contains 5 satisfaction items from the WHOQOL-BREF. These items cover overall quality of life, satisfaction with health, daily activities, relationships, and living conditions. The WHOQOL-BREF and the WHOQOL-5 have been developed for cross-cultural comparisons, and their psychometric properties have been examined in several countries.⁵¹⁻⁵³ A study by Geyh et al⁵² reviewed the psychometric properties of the WHOQOL-5 in relation to 5 other measures of QOL to examine the cross-cultural validity of these scales across countries, using Rasch analysis. Results showed that the WHOQOL-5 has superior properties to the other measures, with the exception of the Personal Well-being Index (PWI),⁵¹ which also scored highly in terms of cross-cultural validity. All other measures showed potential measurement errors, with the comparability and interpretability of scores not being consistent across countries.

Based on the need for common metrics to assess QOL among persons with SCI worldwide, another

group of SCI investigators developed a set of basic items to be used cross-culturally. The development of the International SCI QOL Basic Data Set been described by Charlifue et al.⁵⁴ Its purposes are 2-fold: (1) to standardize the collection and reporting of a minimal amount of information necessary to merge and compare results of published and unpublished studies on QOL, and (2) to provide minimal information that together can be collected in routine clinical practice.

The International SCI QOL Basic Data Set includes 3 items: (1) Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole in the past 4 weeks? (2) How satisfied are you with your physical health in the past 4 weeks? (3) How satisfied are you with your psychological health, emotions, and mood in the past 4 weeks? All items are rated on a scale of 0 (*completely dissatisfied*) to 10 (*completely satisfied*). The items have not been examined for their psychometric properties. Charlifue et al⁵⁴ recommended that these properties be examined in future research.

The QOL Basic Data Set items were translated into Brazilian Portuguese following published guidelines⁵⁵ and were tested with a sample of persons with SCI in Brazil.⁵⁶ Interrater reliability ranged from .65 to .77. The Brazilian sample included 50 persons with chronic SCI who were chosen randomly from among outpatients at the University of Sao Paulo Clinical Hospital. Subjects were classified with paraplegia (58%) and tetraplegia (42%). Subjects were on average 45 years old. Time since injury varied: 40% with less than 6 years, 24% with between 6 and 12 years, and 36% with more than 12 years. The English version was tested in a US sample that was also administered the WHOQOL-BREF. The US sample consisted of 75 persons with SCI who were recruited from outpatient clinics at the University of Michigan Health System. In terms of their neurological status, 48% were classified with paraplegia and 52% with tetraplegia. Their average age and time since injury were 53 and 19 years, respectively. To ease the process of data collection at both sites, interviews were conducted with persons with SCI over the phone and during clinic visits. Interviewers included a

Table 1. International SCI QOL Basic Data Set quality of life items: Scores for Brazilian (BR) and US samples

Item	BR (SD)	US (SD)
1. Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole in the past 4 weeks?	7.14 (2.23)	7.00 (1.91)*
2. How satisfied are you with your physical health in the past 4 weeks?	6.62 (2.55)	5.54 (2.41)
3. How satisfied are you with your psychological health, emotions, and mood in the past 4 weeks?	7.80 (2.18)*	7.28 (2.01)*

Note: QOL = quality of life; SCI = spinal cord injury.

*Scores differed from those for item 2, $P < .005$.

Table 2. Spearman correlations between International SCI QOL Basic Data Set items and WHOQOL-BREF indices

Variables	International global satisfaction	International satisfaction with physical health	International satisfaction with psychological health	WHOQOL-BREF overall QOL
Satisfaction with physical health	.58	—	—	—
Satisfaction with psychological health	.64	.69	—	—
WHOQOL-BREF overall QOL	.64	.62	.54	
WHOQOL-BREF general health	.47	.64	.44	.61

Note: $N = 75$. $P < .0005$ for all correlations. QOL = quality of life; SCI = spinal cord injury; WHO = World Health Organization.

nurse (United States) and 2 resident physicians (Brazil).

No differences were observed in terms of how the 2 samples rated their QOL for the 3 items. **Table 1** describes the scores for both samples. Within each sample, scores were significantly lower for item 2 concerning satisfaction with physical health than they were for item 3 concerning psychological health ($P < .005$). In the US sample, scores on item 2 were also significantly lower than those on item 1 concerning global life satisfaction ($P < .005$). Similarities between the scores from the 2 countries suggest good preliminary concurrent validity for the translated version of the QOL Data Set. Although there were no differences in scores as a function of gender in the Brazilian sample, women had significantly higher scores for the first ($P < .01$) and third ($P < .05$) items in the US sample.

Results suggest possible low sensitivity for these 3 items in detecting differences between subjects and across samples. To address some of these issues, the authors conducted additional analysis in the US sample to preliminarily determine validity for these items. The WHOQOL-BREF was collected during the same interview in this sample. The International SCI QOL Basic Data Set items were strongly associated with each other and with the WHOQOL-BREF's measures of overall QOL and general health, suggesting good preliminary validity for the international items. **Table 2** shows these results. All Spearman's correlations were significant at $P < .0005$. Correlations among the Basic Data Set items ranged from $r_s = .58$ for the relationship between global satisfaction and satisfaction with physical health to $r_s = .69$ for the relationship between physical and psychological health. The WHOQOL-BREF measure of overall

QOL was most highly correlated with the International SCI QOL Basic Data Set global satisfaction item ($r_s = .64$), whereas the WHOQOL-BREF measure of general health was most highly correlated with the International SCI QOL Basic Data Set item on physical health ($r_s = .64$). Women with SCI had higher scores on all 3 items from the International SCI QOL Basic Data Set and both WHOQOL-BREF measures, with these differences being statistically significant ($P < .05$) for Basic Data Set items on global satisfaction and psychological health as well as WHOQOL-BREF measure of overall QOL.

Another international study of QOL using 4 generic life satisfaction measures (Satisfaction With Life Scale, LiSAT-9, PWB, and the WHOQOL-5) and including participants from Australia, Brazil, Canada, Israel, South Africa, and the United States found that country explained 5% of the variance in a multivariate context, with persons from Brazil having the lowest levels of QOL and those living in the United States having the highest.⁵² The study also noted that in non-SCI populations, differences in QOL across countries are dependent upon the measures used. Another study that used the same sample and 4 QOL measures found indications of cross-country bias in all of 4 measures.⁵¹ In a non-SCI study, Diener and Suh noted that differences in QOL across countries exist, with levels tending to be higher in wealthier ones, and stated that “the wealth of nations also correlates with human rights, equality between people, the fulfillment of basic biological needs and individualism.”^{57(p436)}

International Measures of QOL for SCI: Future Directions and Recommendations

This article describes how QOL is defined and conceptualized. Cross-culturally, the concept has been assessed in many ways, evolving from an economic indicator to what is currently primarily understood as a subjective construct including happiness and overall well-being along with social, functional, and health status. A review of definitions suggests that QOL is a dynamic interactive concept based on personal experiences, environmental factors, and health. Differences between health and disability for persons with

SCI are also acknowledged and must be taken in consideration when future QOL assessments are designed. Qualitative findings provide further evidence of the importance of subject assessments.

The need for individualization and specificity is currently reflected in the trend toward increased development and use of PROs. QOL is viewed as subjective and personal, reflecting a person's expectations and ability to do things. Personal factors need to be understood in the context of environment, including access to appropriate health care and resources required to live independently with SCI, and personal and societal values. Relationships among these factors appear to differ significantly between countries. Our quantitative findings suggest that there is good reciprocity between international assessments of QOL when tested in 2 countries, Brazil and the United States. Although the lack of significant differences between QOL in the 2 samples suggests that the International SCI QOL Basic Data Sets can be used across nations, judgments are seemingly contextualized to what is deemed normal and expected by respondents in different cultures. These findings may also suggest that the 3 items comprising the QOL International Data Sets may be insufficient to fully capture the QOL construct. It is nevertheless a step in the right direction, especially given the high correlations with a well-accepted measure, the WHOQOL-BREF.

Finding a common metric for QOL will allow comparisons to be made across countries and will enhance the promotion of policies that ensure equality and reduce disparities. The International SCI QOL Basic Datasets represent a promising approach to the collection of QOL data by providing a common measure of QOL. Data can be used to compare results of clinical trials and other interventions for persons with SCI and to assess outcomes of social and disability policies. Further studies with larger samples are necessary to ensure the reliability and validity of measures and items designed to assess QOL across nations.

We have several recommendations to ensure that measures of QOL for SCI are cross-culturally valid. The use of IRT, including Rasch analysis, offers a means of testing instrument validity for cross-cultural use. Differences between

countries assessed by various instruments should accurately reflect cross-culturally valid differences in responses to individual items, thus avoiding cross-cultural bias. When using IRT, differential item functioning analyses should address not only cross-cultural biases but also demographic, injury-related, and other factors as described by the ICF framework.⁵¹ As summarized by Post,⁵⁸ 3 steps are recommended when the Rasch analysis approach is adopted: (1) Do the data fit the stranded Rasch Model? If so, items are assumed to measure only one concept and item scores follow an interval scale. (2) Do the response scale categories follow a successive order? If so, these categories accurately differentiate scale steps. (3) Do the data fit in different countries? If so, results from different countries can be compared. Special attention should also be placed on the quality of language translations to ensure the relevance of constructs across cultures.

Whenever possible, the selection of QOL outcome measures should take into consideration their psychometric properties and use within the

SCI population. Recently, the National Institute of Neurological Disorders and Stroke (NINDS) developed common data elements (CDEs) for QOL to be used in clinical trials related to SCI. A number of QOL measures were reviewed by a panel of experts and recommendations were made as to the suitability of these measures for such trials.⁵⁹ It is the intention of this effort by NINDS and the professional societies representing SCI research and clinical care, such as the American Spinal Injury Association and the International Spinal Cord Society, that with the development of international datasets and CDEs, common tools and metrics will become available to investigators worldwide who are interested in pursuing SCI research. The use of these resources is encouraged to promote a coordinated effort across disciplines, nations, and cultures to collect, share, and compare valid data on QOL after SCI.

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